# Principles, Core Functions, and Performance Measures for Integrated Child Health Information Systems: Collaborative Development


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# Outline of presentation

- **Background on integrated child health information systems (ICHIS)**
- **Collaborative development of principles and core functions**
- **Collaborative development of performance measures**
- **Review performance measures**

# Why do we need integrated CHIS?

- Many children do not receive all preventive or therapeutic services in a timely manner
- Several studies have found low immunization coverage rates to be correlated with insufficient screening for lead and anemia
- Multiple PH programs focus on the same target population w/o coordination of services & outreach
- There is a need for population-based information that can better identify at-risk children and target programs and services to their needs

# Goal of integrated CHIS

**To provide all appropriate information to patients/families, providers, and programs**

- **Complete, accurate & timely information ⇨ improved service delivery and health outcomes for children**
- **Integration - providing a range of information to the end user in a simple, comprehensive format so he/she can readily take all indicated actions**
- **Integration relates to the end user, not to the background machinery**

# Our approach

**As a non-profit, non-governmental organization we…**

- **Act as a neutral convener**
- **Provide a field-oriented perspective**
- **Use a collaborative, participatory approach**
- **Stimulate new ideas and innovative solutions—challenge the status quo**
- **Advocate/educate partners**

# Targeted programs/systems for integration

- Immunizations (immunization registries)
- Newborn dried blood spot (NDBS) screening
- Early hearing detection and intervention (EHDI)
- Vital registration

# Why these?

**4 areas chosen share characteristics:**

- **Recommended for all infants/children**
- **Carried out/begin in newborn period**
- **Time-sensitive**
- **Primarily delivered in private sector but have strong public sector component**
- **Mandated in most/all states**

# Core Workgroup Meeting
# May 8-9, 2003

- **Goal – Develop a draft ….set of core functions…for ICHIS**
- **Objective – To gain agreement on the draft core functions**

# Core Workgroup Meeting Participants - 1

- Delton Atkinson, NCHS
- Tonya Diehn, IA
- John Eichwald, UT
- Jennifer Heberer, ME
- Therese Hoyle, MI
- Pam King, OK
- Robert Cossack, MA
- Donna Williams, NNSGRC
- Amy Zimmerman, RI

# Core Workgroup Meeting Participants - 2

**GSB/MCHB/HRSA**

- Deborah Linzer
- Michele Lloyd-Puryear
- Marie Mann

**AKC/PHII**

- Sherry Bolden
- Nicole Fehrenbach
- Alan Hinman
- Janet Kelly
- David Ross
- Kristin Saarlas

# Core Workgroup Meeting - 1

- **Framework for Integrating Child Health Information Systems**
  - **Set of activities/functions to achieve desired outcome – improving health of all children**
  - **Focus on integration of selected program information systems**
  - **Builds on approved practices and standards**
  - **Provides minimum set of core functions**
  - **Is not a technical model**

# Core Workgroup Meeting - 2

- **Reviewed existing programmatic standards/guidelines/recommendations**
- **Reviewed existing functional standards (immunization registries)**
- **Compared 12 registry core functions to immunization standards to see if they will meet the standards (yes)**

# Core Workgroup Meeting - 3

- **Reviewed standards/guidelines/recommendations for other programs and discussed how registry core functions would have to be modified/expanded to meet them**
- **Developed (with subsequent comments) 19 principles, 22 core functions and 8 desirable functions**

# Points to keep in mind

- **Principles/functions refer to integrated systems – individual program systems may have additional functionality**
- **Do not speak to**
  - **System architecture**
  - **Data elements**
  - **Software**
- **Address what the functions are, not how they are to be achieved**

# Principles underlying integrated child health information systems

- **Purpose – 1**
- **Security & confidentiality – 5**
- **Technology serving stakeholder needs– 8**
- **Quality assurance & evaluation – 3**
- **Financing – 2**

- **Total – 19**

# Core Functions of Integrated Child Health Information Systems

- **Confidentiality & security – 5**
- **Establishing & maintaining client records – 4**
- **Service functionality – 6**
- **Technical functionality – 4**
- **Reports – 3**

- **Total – 22**

# Desirable functions of integrated child health information systems

- **Establishing & maintaining client records – 3**
- **Service functionality – 2**
- **Technical functionality – 1**
- **Reports – 2**

- **Total – 8**

# Subsequent steps

- Review by external review committee
- Further modification
- Submission to GSB/MCHB
- Presentation to grantees
- Publication in JPHMP

# Participants in Performance Measures Workgroup Meeting, March 9-10, 2004

- Ellen Amore, RI
- Paul Biondich, IN
- Richard Harward, UT
- Jennifer Heberer, ME
- Gary Hoffman, WI
- Therese Hoyle, MI
- Pam King, OK
- Robert Kossack, MA
- Garland Land, MO
- Charles Rothwell, NCHS
- Sherry Spence, OR
- Donna Williams, NNSGRC

# Participants in Performance Measures Workgroup Meeting. March 9-10, 2004

**HRSA**

- Michael Kogan
- Jeffrey Koshel
- Deborah Linzer
- Michele Lloyd-Puryear
- Marie Mann
- Jacob Tenenbaum
- Karen Thiel

**AKC/PHII**

- Nicole Fehrenbach
- Alan Hinman
- John Kiely
- Patricia Richmond
- Kristin Saarlas
- Ellen Wild

# Performance Measures Workgroup Meeting, March 9-10, 2004

- **Objective - Develop a draft set of performance measures to measure an integrated child health information system's ability to perform core functions**
- **Process – Review principles and core functions of integrated CHIS and discuss possible indicators of performance**
- **Outcome – System functionality checklist and Performance measures**

# Qualities of good performance measures

- **Combination of process and outcome measures**
- **Feasible to measure on an on-going basis**
- **Sensitive to change over time**
- **Change must mean something (e.g., progress, problems)**
- **Valid and reliable**

# Things to keep in mind

- **The focus is on the integrated information system—not the individual programs**
- **Measures need to support overall goals and help measure targets**
- **You can't fatten a cow by weighing it everyday (measurement is not the same as progress)**

# Subsequent steps

- Review by outside review group
- Site visits with intensive discussions both principles/core functions and performance measures
- Revisions of both documents based on the above
- Workgroup meeting Jan 27-28, 2005

# Participants in workgroup meeting, Jan 27-28, 2005

- Ellen Amore, RI
- Pat deHart, WA
- Richard Harward, UT
- Gary Hoffman, WI
- Therese Hoyle, MI
- Pam King, OK
- Robert Kossack, MA
- Garland Land, MO
- Maureen Mitchell, VA
- Charles Rothwell, NCHS
- Lori Sanchez, CO
- Sherry Spence, OR
- Donna Williams, NNSGRC

# Participants in workgroup meeting, Jan 27-28, 2005

**HRSA**

Mary Kay Kenney
Michael Kogan
Deborah Linzer
Michele Lloyd-Puryear
Marie Mann
Bonnie Strickland
Jack Tenenbaum
Elizabeth Walkup

**PHII**

Nicole Fehrenbach
Alan Hinman
John Kiely
Kim Koporc
Ellen Wild

# 1A - Percent of newborns with a record in the integrated child health information system (ICHIS)

# PM 1B - Percent of records of live births occurring in the jurisdiction that were established within 0-2, 3-7, 8-14, 15-30, and >30 days of birth

# PM 2A - Percent of records that include data on dried blood spot screening, hearing screening, immunization, and vital registration

# PM 2B - Percent of records that include data on the four program elements (dried blood spot screening, hearing screening, immunization, and vital registration) within 90 days of birth

# PM 3A - Percent of records with immunization information available

# PM 3B - Percent of records with immunization information available within 30 days of administration

# PM 4A - Percent of records with newborn dried blood spot screening information available

# PM 4B - Percent of records with newborn dried blood spot screening information available within two days of report from laboratory

**(Note: Once initial newborn dried blood spot screening results are reported.)**

# PM 5A - Percent of records with newborn hearing screening information available

# PM 5B - Percent of records with newborn hearing screening information available within specified time intervals for screening – 0-2, 3-7, 8-14, 15-30, >30 days of birth

# PM 6 - Percent of children with hearing results of “refer” who have been evaluated by 6 months of age and are enrolled in/referred to an early intervention or other appropriate program OR found not to have hearing loss

# PM 7A - Percent of children with non-normal congenital hypothyroidism screening results who have been evaluated and are under appropriate management by 30 days of birth

# PM 7B - Percent of children with non-normal hemoglobin screening results (except traits) who have been evaluated and are under appropriate management by 6 months of age

# Next steps

- Final review by outside group
- Pilot testing in 5 sites
  - MO, OR, RI, UT, WA
- Further modification based on pilot test
- Test in other sites (?)
- Publication

# Conclusions

- **Development of principles and core functions of ICHIS establishes what they must do**
- **Performance measures can tell whether and how well they are implementing the principles and core functions**
- **Collaborative approaches enhance the likelihood of good outcomes**